



Pediatric Congenital  
Heart Association

## Statement for the Record

In support of

**H.R. 3952,**

**“The Congenital Heart Futures Reauthorization Act of 2015”**

Submitted to the Subcommittee on Health,

House Committee on Energy and Commerce

September 8, 2016



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On behalf of the estimated 2.4 million people living with congenital heart disease (CHD) in the United States, and the countless families who have lost loved ones to CHD, the Pediatric Congenital Heart Association is writing to offer our strong support for H.R. 3952, The Congenital Heart Futures Reauthorization Act of 2015, or CHFRA.

We are extremely grateful to Representative Bilirakis and Representative Schiff for their steadfast leadership as sponsors of this bipartisan effort to build upon existing programs which track the epidemiology, raise the awareness and promote lifelong research of the most common birth defect. Thank you, also, to the dozens of congressional cosponsors committed to this goal. We also want to express our appreciation to the leadership of the Energy and Commerce Committee and the Health Subcommittee for this opportunity to move this important bill toward enactment.

### **The Burden of Congenital Heart Disease**

CHD, a structural abnormality of the heart present at birth, is the most common birth defect and the leading cause of birth defect-related infant mortality. Nearly 1 in 100 babies are born with CHD and more than five percent of those with CHD will not live to see their first birthday. Even for those who receive successful intervention, **it is not a cure.**

However, critical information about the epidemiology of CHD, the effectiveness of treatments, and lifelong outcomes is seriously lacking, at best, and non-existent in specific areas such as comorbidities that occur later in life.

Over the last several decades, advances in treatment have dramatically improved survival for children with the most complex CHD and increased the life expectancy of adults with CHD. More than 80% of children born with CHD are now expected to survive into adulthood. In the absence of US data, which the Congenital Heart Futures Reauthorization Act will address, extrapolation of Canadian data suggests that there are 2.4 million people with congenital heart disease, more than half of which are adults. This prevalence is expected to increase 5% annually, resulting in a surge of CHD survivors who need life-long specialized cardiac care. Although the growing population of individuals with CHD is a testament to important innovations in CHD care, the reality is that complex CHD and its treatments may result in chronic complications that may require further surgery, intervention, or heart transplantation. In addition to structural heart issues, individuals with CHD are at risk for secondary conditions including kidney, liver, and neurodevelopmental problems. In short, the interventions children with CHD receive are not cures, underscoring the need for lifelong care by expert providers to avoid and treat health complications later in life.

Another challenge faced by those living with CHD is the transition of care from pediatric to specialized adult heart care. In part, this is due to the lack of infrastructure, providers, and payors required to care for the ever increasing adult CHD population. Adding to this challenge are those patients who no longer seek care believing their childhood intervention has “cured” them, or that they are well enough to no longer need specialized cardiac care. Estimates suggest less than 25% of adults with CHD are

receiving appropriate subspecialty care. This population of patients who are lost to follow-up care present a critical public health issue, which will be addressed by this important legislation.

Neurological complications related to CHD pose another challenge. Cardiac surgery and perioperative treatments in the infant put the developing brain at tremendous risk for injury and long-term neurodevelopmental complications. Survivors often suffer injury to the brain due to low oxygen levels resulting from their CHD as well as operative and perioperative interventions. These brain injuries result in decreased neurodevelopmental, psychosocial, and physical functioning, and can significantly negatively impact the individual's growth, performance, and quality of life.

### **The Cost of Congenital Heart Disease**

People born with CHD require lifelong, costly, specialized cardiac care, and face an ongoing risk of permanent disability and premature death. As a result, healthcare utilization among the CHD population is disproportionately higher than the general population. It is estimated that compared to medical costs of care for their peers, the medical costs for individuals with CHD are 10 to 20 times as great. Inpatient care costs (not including costs of physician care) for patients < 21 years old with CHD alone totaled more than \$5.6 billion in 2009, representing 15 percent of hospitalization costs for all patients in this age range. Around half of all dollars spent on pediatric CHD related inpatient stays is paid by Medicaid.

Hospital admissions for adults with CHD roughly doubled between 1998 and 2005. Nearly 20% of these admissions were for cardiac surgery or catheter-based intervention. Healthcare utilization and costs continue to rise, due to hospital admissions, surgery and intervention, and emergency room visits. For example, with improved longevity to childbearing age, the number of high risk annual births in women with CHD is increasing. Childbearing women with CHD are fourteen times as likely to experience cardiovascular complications during pregnancy and are eighteen times as likely to die from such complications as are women without CHD. They also have longer hospital stays and incur higher hospital charges.

With disproportionate medical costs, it is critical for us to understand the life-course of those living with CHD, their health care utilization and potential cost reduction strategies.

Consider the story of Piper, who is one in 100. Piper was born on Independence Day in 2003 after a seemingly normal pregnancy. However, instead of rosy pink, Piper was born blue. Suddenly, the world was flipped upside down for her first-time parents, as they learned that there was something critically wrong with Piper's heart. She was rushed to the nearby children's hospital to receive life-saving treatment which included open heart surgery. Her recovery from 14 hours of surgery was challenging and Piper spent the next 6 weeks in the hospital. Imagine that she has since grown to become a vibrant adult having completed college and entering the work place. At her annual visit she expresses plans to become pregnant, soon. Her physician, after reviewing data,

refers her to a high risk obstetric center, and modifies her medications for heart rhythm problems. She delivers a healthy baby boy a year later, without complications for herself or her child. But, this data her physician referenced doesn't exist. Instead this current teenager is left with questions like can I travel to attend college? Will I be able to have children? How long am I expected to live? Her life remains extraordinary with ongoing, costly, specialized care and concerns about a future where long-term outcomes are widely unknown.

### **A Critical Public Health Issue**

The Congenital Heart Futures Act of 2015 (CHFRA) offers a reasonable and meaningful solution. To improve care and reduce costs, it is essential that Congress enacts legislation supporting improved understanding of CHD across the lifespan. The CHFRA calls for improved public health research and surveillance of those living with CHD, as well as providing for education and awareness, that will help us better understand and improve long-term outcomes for Piper and the more than 40,000 babies born with CHD each year.

Previous Congressional investment for CHD activities supported by the Centers for Disease Control and Prevention's (CDC's) National Center on Birth Defects and Developmental Disabilities (NCBDDD) has funded the development of innovative surveillance strategies among children, adolescents and adults with CHD. This has led to the standardization of research methods and an increased understanding of the public health burden of this condition. Since the enactment of the Congenital Heart

Futures Act in 2010, Congress has appropriated nearly \$15 million to NCBDDD for these activities. Continued federal investment is necessary to provide surveillance and public health research on individuals across the lifespan to better understand CHD at every age, improve outcomes and reduce costs.

The Congenital Heart Futures Reauthorization Act of 2015 does just that. The legislation directs the Centers for Disease Control and Prevention (CDC) to plan, develop and implement a representative cohort study to help describe basic U.S. demographics of the disease, assess healthcare utilization, and lead to evidence-based practices and guidelines for CHD care. The bill also allows for the CDC to establish and implement an education, outreach and awareness campaign directed at CHD across the lifespan, to ensure that those who have a CHD, and their families, understand their life-long healthcare needs and maintain appropriate specialized care.

The CHFRA also directs the National Institutes of Health (NIH) to assess its current research into CHD so we can have a better understanding of the state of bio-medical research as it relates to improving understanding of causes and drive innovative and effective treatments for CHD and related disease processes.

Congenital heart disease is common and costly; a critical public health challenge. We are thankful for the many members of Congress and colleagues in the community who join us in support of support of H.R. 3952, the Congenital Heart Futures Reauthorization Act 2015. It is essential for Congress to pass this comprehensive

approach to CHD that will address a critical public health issue and lead to better care, outcomes and quality of life for the millions of individuals living with CHD.

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The Pediatric Congenital Heart Association's mission is to "Conquer Congenital Heart Disease." We are founded on the key purpose to be the resounding voice of the pediatric patient population and are accomplishing this through collaboration with patients, parents, providers, and partner organizations in order to improve quality and outcomes through CHD education, research and awareness.